

## **Draft Minutes of the July 14, 2004 Mental Health Planning Council**

Meeting convened the meeting at 10:15

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A membership committee meeting preceded the council meeting.

**Thank you Bill Yolton for taking these excellent minutes.**

**Attending: Guests are noted with \*.** Kate McBride, Arthur Kate, Alicia Bush PW CSB for child and family council, Shirley Ricks\*, Lynn Chennault, John Bennett for Dennis Waite, Catherine Hancock, Janet Lung, Will Ferriss, Amber Ann (eighth grade)\*, Joyce Kube, Lynn DelaMer, Ray Bridge, Ann Cutshall, Cynthia Power, Van Avery, David Mangano, Chesterfield CSB\*, Julie Brodie, Pam McLaughlin\*, Dana Traynham, Dawn --- \*parent of a consumer & CELT grad., Vicky Fisher, Mitch Mitchell for Jack Wood, Bill Yolton, Mary McQuown for the REACH program, Val Marsh, NAMI VA, Mary Kay Johnston DRS. Irene Walker-Bolton (Dept. of Ed.), Margaret Nimmo Crowe, Rebecca. Arriving for the afternoon agenda: Jim Martinez, James Reinhard\*, Jack Wood, Michael Shank. There were regrets from Linda Edwards, Paul Cook and Sherry Rose. Absent Brian Parrish and Nancy Ward.

Dawn mentioned that she has learned that services for adolescents are absent in Virginia.

Ray Bridge made his usual failed attempt at humor directed toward CSBs

### **Council Priorities**

Ray Bridge noted the Planning Council has adopted five priorities to focus our work:

Educate Virginians about the need for children's services

Promote recovery and recovery services for adults with mental illness

Hold a legislative forum in advance of the General Assembly

Become more diverse in our membership

Monitor funding for and restrictions on medications provided by the state pharmacy, Medicaid and other sources

### **Membership Committee meeting report:**

Cynthia Power, chair: While it would be nice to have a 50 person Council, it would not be wise to increase rapidly, but to bring a few more people to the retreat in October, who really want to be members. There do some orientation and people could back out if they want to. Broaden our cultural diversity. Get a representative from IAPSRS, the clubhouses. Review participation of those who have not been able to attend meetings.

**Partnership Plan for 2004/05** (Virginia must submit this to the feds as a condition of getting the block grant)

Janet Lung and Will Ferriss, who administer the Virginia block grant, reviewed the nature and process of Virginia's Partnership plan with the CMHS (the Center for Mental Health Services). September 1 is the CMHS deadline. The Dept. plans to submit it on August 25<sup>th</sup>.

Virginia still meets the test for "maintenance of effort" in funding (to qualify for the mental health block grant,) despite state budget cutbacks in recent years. We have also met the set aside for children's services. Virginia fell below the maintenance of effort funding threshold required to get the substance abuse block grant. The Department went back to the legislature to get more funds to requalify.

Janet noted that the Planning Council has seen the contract evolve over the years. As the planning process began to be linked to outcomes, the council moved away from the visionary plans, to a more conservative pattern. The Feds now want information in data tables. [Last year the performance contract had 12 tables recorded on paper.] The data tables have leveraged a sea change in the way we collect data. CSBs now have to file a lot of statistics with the Department, using the CCS (combined community submission??). They can extract the needed data from their own data software, which varies among CSB.

Will explained that for the first time, each consumer in community services in the CCS data system has a unique identifier so that their treatment history in hospitals and CSBS can be tracked, but that identifier is encrypted for privacy. (The data system does not extend to the criminal justice system). With a unique identifier we can more accurately count the number of people served what treatment they got, their demographic characteristics, etc.

States are expected to meet the outcome targets that they agree to in their partnership plan; failing to do so could result in a 10% cut in the block grant. Therefore the Department has lowered targets to be sure that we meet them.

Several outcome measures reported in the block grant are based on responses to separate surveys for children's services (given to parents) and for adult services, (given by CSB's to people who come for services during a given week). The Council questioned the usefulness of the adult survey, which includes some satisfaction indicators derived from a "consumer report card" developed by the CMHS. Bill Yolton pointed out that the satisfaction survey is not worth much. It is constructed without validity questions, and there's a tendency for it to report in a favorable bias. Only those who show up are surveyed. Bill said there's a Stockholm syndrome in which not only do consumers think favorably of their captors, but they also have no standard for comparison – i.e., compared to what? Pam McLaughlin pointed out that she never received a questionnaire in ten years of receiving services from the Fairfax Falls Church CSB and wondered how consumers learn about the opportunity to fill one out. The Council questioned how to get a more complete response—for example giving consumers a heads-up in advance or mailing questionnaires. Lynn Chennault said that a mailed response will get a lower response rate and will cost more. Janet said that the children's survey is mailed to parents of children receiving services; the return rate is 27 percent. Will said that the adult services survey is already quite costly, and mailing would increase costs.

Val Marsh pointed out that NAMI VA has recently done a mailed survey in cooperation with Virginia Commonwealth University and the Virginia Office of Protection and Advocacy. They have had a high response in cards from people who responded. (clarify)

There were suggestions that the reporting week for the adult survey be at another time. Bill Yoltan urged that there be consumer run reviews to measure satisfaction with services and evaluating the adequacy. He mentioned a number of states that use teams of consumers, families and professionals who make unannounced visits to mental health agencies and talk to all concerned. Val pointed out that Georgia's reviews conducted by consumer/family teams led to the Olmstead vs. LC supreme court case. New York NAMI used its survey results to change the system.

In discussing recovery, Jack Wood has asked what is it we're measuring? The VACSB (Virginia Association of Community Services Boards) has an outcomes committee, and that might be worth pursuing.

Ray Bridge expressed the Council's view that there should be greater accountability and outcome measurements for the bulk of the mental health block grant, which is turned over to CSBs with no strings attached. Lynn Chennault pointed out that block grants funds (that his CSB receives?) account for only about 10% of his funding. Ray also expressed concerns about the allocation of these funds among CSB's which is based on the amount of federal funds they drew down before the advent of the block grant rather than competitive criteria or population. Will Ferriss noted that some CSB programs were initiated from federal funds and are now grandfathered into each CSB's allocation.

Lynn Chennault said that some of the tracking of those funds has been lessened to relieve the administrative burdens, on CSBs.

### **Children's Services Committee Report: planning for conference**

Margaret Nimmo Crowe: The Children's committee is planning for a conference on children's services. The conference will explain what a system of care should be. We are working with the Partnership for Individuals with Disabilities. The conference is planned for Oct. 20-21 in Roanoke. The goal is to have 200 folks who work with children, parents, advocates Keynoter: Beth Stroul from Northern Virginia who has pioneered on developing a children's system of care.

### **Federal children's legislation**

Margaret will distribute information about reports from the U.S. Senate hearing on children's services and other legislation that is in the works. She will add Virginia facts to it.

Val Marsh says that she is getting different information on the proposed legislation in Congress than children's advocates are providing so is at a loss to advise her organization. Margaret will consult with Val in providing the summary so that pros and cons are included.

### **Virginia Study on relinquishing custody for treatment**

Margaret said that in Virginia, a legislative study going on of the CSA (Comprehensive Services Act) about parents having to relinquish custody of their children in order to gain services for their kids. Will take the study to the legislature by November 1<sup>st</sup>. The Council discussed the devastating consequences of the practice. Bill Yolton (?) mentioned that the Federation for Families and the Bazelon Center have done a lot of work on this topic. Margaret said that two parents who have faced this are on the state work group looking for a solution.

Margaret explained that parents who make too much to qualify for CSA funding have to give up their children to get services. Mandated services are in foster care. Only 8% of the funds go for non-mandated kids. Of all the kids who need the services, it is something like 10% who get them, says Val, added that it was designed this way to keep the costs down. (Note: I believe that CSA funding amounts to nearly \$300 million a year—Ray Bridge).

Children in need reach a crisis point so that there is no way to pay for them, sometimes families have their children arrested or give up their child to foster care. That's the issue we're trying to get at. Val says that by the time the NAMI crisis line gets calls from families, things are already past the point of no return, the cops are at the door. We're putting systems that were not designed to provide mental health services to provide those services. (Margaret circulated a Congressional study that shows that thousands of children are sent to juvenile detention simply in order to await mental health treatment, and they can stay there a long time with no treatment.)

Pam McLaughlin raised the issue of how foster care views parents. There's a bias from the origin of the foster care system to protect children from parental abuse and neglect. The system can stigmatize the parents who are trying to get help for their SED or SMI or child.

### **Children in juvenile detention and reform schools**

In response to a question regarding placing children in detention to await mental health treatment, (name?) from the Department of Juvenile Justice explained that when kids come into one of the seven State Juvenile Justice centers, they have been adjudicated, and are a ward of the state. A good percentage are with diagnosable mental health disorders. There are barriers to treatment, such as emphasis on security, with fencing erected under Gov. Allen's term. There are some 70 psychologists at work, but often treatment cannot be provided, for example, when there is a lockdown.

Shirley Ricks: Administrators are concerned that a lot of kids are in the justice system because they can't get mental health services. There is a contract to provide MH services in centers. Ray: a good thing for the regional partnerships to address.

Difference between state correctional systems where there are mental health services and the local juvenile detention centers where there are few services. Estimate that 60% in the juvenile facilities have mental health problems, but the correctional system is for punishment not healing.

After lunch, the Council reconvened.

### **Council Budget**

**Carryover of the 2003/04 budget: (\$30,000)**

Executive Committee proposals from May 19, July 12:

\$10,000 Recovery Promotion activities  
\$ 5,000 Award program for exemplary services in Virginia  
\$ 3,000 CELT Advance Training for consumer mentors and leaders  
\$ 4,000 Planning Council Brochure/ Powerpoint presentation  
\$ 3,000 Develop a website, to be hosted by the Department  
\$ 1,500 Hold a forum on mental health legislative initiatives for 2005 and beyond  
\$27,000 Subtotal  
\$ 3,000 unallocated

Ray Bridge reported that the items on the agenda were the product of the Executive Committee discussion. Leading the items is \$10,000 to promote the Recovery orientation in the Commonwealth.

After discussion, it was moved, seconded and passed that the proposed budget be approved.

Ray presented a request of Consumer Empowerment Leadership Training (CELT) to the Council for \$3,000 in additional funds to conduct an advanced training program for graduates willing to serve as mentors to others. [Note: I believe that the CELT request was approved as part of the overall \$30,000 budget. Is this correct? Ray]

**Services for people with sensory impairments**

Ann Cutshall asked how persons with sensory impairments can get help in the mental health system. The persons may request services in advance, and normally the services are then provided. Katherine Baker provides coordination for those services for the Department. State facilities are required to provide those services.

**Funding increase for CELT**

Ray Bridge urged that the Department increase the block grant allocation to CELT from \$75,000 to \$100,000 because there is a waiting list for training and because CELT graduates need ongoing support and training.

He suggested that any savings left from the \$2.3 million of the block grant allotted to paying for medications be diverted to pay for it. Jim Martinez said that the savings were one time savings and nobody knows what the situation will be, and it is anticipated that there will be no surplus in the next year. Val Marsh said that she is concerned that ongoing needs should be funded on ongoing basis.

Mary McQuown reported that Mental Health Association of Virginia did request funding of \$100,000 for CELT, but were continued at the previous level of \$75,000 though on a permanent basis. Vicky expressed her thanks that the Department has made funding CELT permanently. Pam McLaughlin reported how much CELT has meant to her; after graduating she has become involved in a number of committees and presentations. Yoltan moved, McQuown seconded, that

the Council approve the request of the Department to increase funding to CELT by \$25,000. The motion passed. Ray reported this action on to the Commissioner who joined the meeting.

### **Access to Medications**

The Council discussed state policy on the formulary of medications covered by Medicaid. Medicaid has engaged a company to review all medications. So far, anti-anxiety meds and anti-depressants (SSRIs) have been exempted from preferred drug list, which prescribes what medications are allowed. If the PDL restricts access to these drugs in the future, there will be a serious problem for people who rely on those meds. Catherine Hancock, who represents the Department of Medical Assistance Services, reported that every appeal from the PDL has been approved.

### **Legislative forum on mental health issues**

Ray discussed the Council's priority to hold a legislative consultation among groups concerned with mental illness. Ray observed that a number of these groups develop narrow agendas separately but do not compare notes and present a unified program to the General Assembly. Last year, as a result, the Virginia Coalition for Mentally Disabled Citizens had a minimal proposal for new mental health funding; it is up to us as a community to prepare a mental health legislative agenda as the Coalition represents all three disabilities.

Ray noted that not all legislative proposals are concerned with dollars; some are policy changes. He also observed that a long-term legislative agenda is needed as well.

If we hold a forum of this type it would take place in September to review what direction to go. The Virginia Association of Community Services Boards will have a legislative discussion at its October 6 meeting. The Mental Health Association of Virginia has a policy forum on Nov. 4-5. NAMI will be doing the same thing in its October annual meeting. Val mentioned that she has to narrow down and fix on only a couple of issues. The ideal is that we should have some common core issues. NAMI will be taking on housing as an issue.

Bill spoke about his concern as co-chair for the Coalition for Mentally Disabled Citizens that there is no wide consensus among our organizations to bring to that arena, and there is no awareness of what is happening at the national level—for example the New Freedom Commission has introduced new paradigms for mental health services that have not been studied in Virginia. The development of the Commissioner's restructuring proposals and the Departments draft vision are being brought together at the Department's conference on restructuring on Dec. 9-10 where the national agenda will be melded with the state vision.

A list of organizations concerned with mental health services could include:

- All associations represented on the Planning Council
- Virginia Coalition for Mentally Disabled Citizens
- State MHMRSAS Board
- Virginia Assn. of Community Services Boards
- Virginians for Mental Health Equity (Karen Culbert).
- Psychiatric Society of Virginia

Virginia Hospital And Health Care Association (Betty Long)  
Consumer Groups and Consumers: VOCAL, NVMHCA, State network, REACH  
IASPRS

### **Council initiative on recovery services**

The Council held an extensive discussion about recovery. We were joined by Commissioner Reinhard, by Department experts of substance abuse services and mental retardation.

Background documents were circulated including the MHPC mission and Dept. draft vision statements; Recovery, a Consumer's View by Mary Ann Beall, Recovery services—what helps and what hinders? (Executive Summary) and the Long Beach, CA “Village” concept of what constitutes recovery-focused leadership for a mental health agency. Also included were a calendar and overview of recovery activities prepared by Mike Shank and Sharon Koehler.

The question is: What role could the Council play in promoting recovery services?

Promote the concept? To whom and how?

Rewards for Promising Practices?

New Services? New Paradigms? New Policies? New Programs?

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To introduce the recovery discussion, Ray spoke of his journey to recovery, and his feeling that forty years of his life were lost before getting better. He noted that medication was still part of his stability. He mentioned that all of us know consumers who are not getting significantly better with their symptoms, but still make something with their lives.

Ray introduced the draft vision statement for the department that includes empowerment and self determination, which are essential ingredients to achieving recovery. Pam McLaughlin observed that the vision statement does not include equality and dignity, and human rights.

The chart from Long Beach was introduced. Vickie Fisher explained the concept of “360 degree” evaluation of staff performance. Consumers as well as other staff take part in the evaluation.

David [who was speaking?]: It's a tough thing for us to grasp. (especially from the medical community) It doesn't mean people. need to be as practical as possible.

Can recovery early intervention and prevention be added? How can recovery be inclusive of children and adolescents.?

Commissioner Reinhard: We have to cure ourselves first as an organization. The way we end the use of seclusion and restraint, we as a system have to teach each other about it by treating people in the organization with dignity and restraint, to pass it on to the people we serve.

Alicia Bush: In Substance abuse, some folks think recovery is “when you stop using.” But, it is a process. Having some other measures is important. Some meds that work for children don't work later. Want to focus on the strengths they do have, their resiliency.

Val Marsh: I have children with mental illness/disorders, and think the developmental disabilities communities has it together, because they are aware from the beginning. With mental illness it is less clear, with late onset it is less clear. After my career working with homeless and mentally ill people, one thing is clear: People with mental illness are not allowed to make mistakes!

Pam McLaughlin: I work harder than most people. I am working on my mental illness. I don't like it when other people are telling me what to do for my recovery. My idea of recovery is when I don't think about mental illness the whole ding dong day. I would like to go to graduate school maybe.

Vicky Fisher: We all have to manage our illness. We always have to see others' perspective. Agreed with Pam that we must always give hope. Choice, hope, and self-definition of what recovery means for her.

Michael Shank: Apropos of being allowed to make mistakes; as a provider, I remember when I helped a client buy a car, and others persuaded her to drive them around, they got drunk and had an accident. I was shriveling. Until I was assured that having the best interests of others was what was important.

Ray Bridge: Recovery begins with hope. He mentioned that the attending the CELT academy helps transform people. It gives them ideas about their own potential. He mentions a consumer who has been changing for three years as a result of his CELT experience.

Ann Cutshall mentioned how important the emotions are. Mary McQuown assured her that the mental illness affects the part of the brain that affects the emotions.

Mary McQuown stressed the positive mood of CELT and people are encouraged to try what they will; no dreams are dismissed; people are encouraged to have them.

From the SA: "I think it is best defined as living with ..." They are living well, even though they are not drug free. They are on methadone, but they are working and taking care of the family. If you treat people as sick, they will stay that way.

Shirley Shirer: Brought a bunch of handouts. If you keep trying to get ready you will never get there. You have to just do it. Mentioned person-centered planning. Behaviors are a method of communication.

Ray expressed his feeling that many people with MR are much more involved in the community than the MH folks.

Mary [McQuown?]: Supported employment is terribly lacking on the mental health side. I was told I was too high functioning for assistance. For us to go looking for that kind of help [?].

Jim Martinez: Displayed the tree for growing recovery. 101 leaves on the tree for someone to do.



Vicky: Displayed the MHA brochure on the Journey to Recovery. She said that the consumer directed and delivered services is such a part

Mary: planning a kick off for

MHA Nov. 6<sup>th</sup> annl meeting.  
Childrens Conf. Oct. 19<sup>th</sup> & 20<sup>th</sup>.

Retreat for Mental Health Planning Council 21<sup>st</sup> and 22<sup>nd</sup>.

Michael on applying for a systems change grant from CMS. And another grant on housing. CMHS grant to promote goals of the New Freedom Commission for recovery. Talking about doing the ROSI survey here in Virginia. 3 positions moved into the children's services offices. Looking for a mental health consumer to help coordinate some of the recovery related activities part time. To try to look at that self-assessment using the ROSI.

Ray: I think that there are substantial barriers to implementing recovery. There are winners and losers as they take away services to implement recovery. The CSB is beholden to local government. That's the real customer. If somebody dies, they are forgotten. It's very hard to get there from here.

Michael: The work that we need to do may not benefit us today...It's going to be a long hard effort to apply effort to each opportunity that comes up.

Ray: We have a dynamic commissioner, who has turned things upside down, and more has been done than in our memory. In a way, we have to look to the CSBs, they have the memory of what the Commissioner has urged. We are where we are because people like Jim Martinez have taken the opportunity to advance these concerns.

Jim: We are involved at different levels. The film Inside/Outside is very helpful. And awareness of using that film. Vicky and Debbie came to our senior management team and gave a good presentation of REACH and WRAP. We put up on our board all the things that are going on and said we need to have a way to put these things together.

The department has talked about having another restructuring group dedicated to recovery services.

Mary Ann Bergeron will do an institute before the VACSB conf. on consumer services.

Lynn: Would not the Mental Health Planning Council be well advised to examine the state plan/performance plan on how well or not it fits with recovery.

Adjourned at 3:10